

Pain is invisible.

Healthy people have an instinctive revulsion for unhealthy people.

These premises are the source of the majority of difficulties disabled folk have in dealing with the general public.

There is often incomprehension, followed by implied criticism:

"You're not working, then?" "You look really well, though."

"So you haven't got a diagnosis? What's the problem then?"

"Oh, back trouble...I have that too. Keeps me off the golf course now and then, but I put up with the pain."

Body language, if not overt spoken words, often convey a dislike for explanations.

Once in a while, you might even get someone who openly says:

"I don't know what your problem really is, look, you've just got to get on with it."

"We've all got problems, mate." (In other words, "don't bother me with yours!")

This can be very distressing, especially if it comes from work colleagues, who start to see your sick time as "swinging the lead" or acquaintances who are brusque to the point of rudeness.

Some people go the other way: they exude pity from every pore.. this is just as galling, as it treats you like a walking illness instead of a person.

I find the best way around this is to say as little as possible about my illness. This can make difficulties if I am invited somewhere I know I won't be able to sit down, or if I don't know where the nearest loo is. I usually have to invent a credible excuse for not attending.

Really, it is a matter of finding your own way through, and perhaps seeking out the company of either people in similar situations or sympathetic folk who will see you as a person who happens to be inconvenienced by illness.

Try to make sure that you do not isolate yourself from others: cutting yourself off will be bad for you and bad for your family and friends.

However much it is tempting to stop trying to socialise because of pain or fatigue, it is important to try at least to involve yourself in activities with other people. It doesn't have to be hang-gliding or bungee-jumping, it could be playing cards or flower arranging, or simply keeping in touch with friends over the phone.

Remember that you will find company to be like a breath of fresh air if you think about it positively. Even children of family and friends, though tiring, can stimulate you and enable you

to see life through innocent and inquiring eyes.

If you can't go out to a restaurant for evening meals, try a pub lunch: if finances won't run to that, then treat yourself at home. I can't sit through a film at the cinema, but every couple of weeks, my husband and I treat ourselves to a video and a take-away meal. We really enjoy it and it is something to look forward to.

Don't forget, if you isolate yourself, then you may be forcing your partner (and family) to forego social events, or to attend without you, which can be a step towards spending progressively less time together.

Get out there and enjoy yourselves!!

So there it is. Neither the 39 steps, nor even the 12-step AA approach.

Just 7 simple steps on which to base a way forwards.

Luckily our future only happens a day at a time, as that is about the limit of our horizons at times.

I hope this will encourage those fighting chronic illness, both the doctors and the patients, to pool their resources. We need all the ammunition we can get to fight the real enemy (the illness) rather than each other.

And remember:

Misfortune is great, but human beings are even greater than misfortune. (Rabindranath Tagore)...or to put it another way...

We're like tea bags, we don't know our strength until we get into hot water! (Bruce Laingen, Iranian hostage)

Useful reading:

Living Creatively with Chronic Illness Eugenie G. Wheeler, Joyce Dace-Lombard, Ventura 1989